Title

Cognitive and behavioural responses to symptoms in adolescents with Chronic Fatigue Syndrome (CFS): A Case Control Study nested within a cohort

Authors

Loades, M.E.[1,2], Rimes, K. A. [3], Lievesley, K.[3], Ali, S.[4], & Chalder, T.[3,4].

Affiliations

[1] Department of Psychology, University of Bath
[2] Bristol Medical School, University of Bristol
[3] King's College London
[4] South London & Maudsley NHS Trust

Corresponding author contact details & qualifications
Maria Loades, Department of Psychology, University of Bath, Bath, BA2 7AY, England.
Email m.e.loades@bath.ac.uk (+44) 01225 385249; BA(Cantab), DClinPsy

Co-author contact details & qualifications
Dr Katharine A. Rimes, Katharine.rimes@kcl.ac.uk, DPhil, DClinPsy
Dr Kate Lievesley, PhD
Ms Sheila Ali, Sheila.ali@kcl.ac.uk, MSc
Professor Trudie Chalder, trudie.chalder@kcl.ac.uk, PhD

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Conflicts of Interest

TC is the author of several self-help books on chronic fatigue for which she has received royalties. KR has co-authored a book with TC called "Overcoming Chronic Fatigue in Young People".

Abstract

Background: What adolescents think about symptoms and what they do in response could contribute to fatigue maintenance. We compared the cognitive and behavioural responses of adolescents and their parents with CFS (N = 121) to asthma (N = 27) and explored the predictive value of these variables on fatigue and functioning in CFS.

Method: Consecutively referred adolescents with CFS were recruited. Questionnaires, completed by adolescents and parents, assessed fatigue, functioning, mood and cognitive and behavioural responses to symptoms. Age matched adolescents with asthma completed the same questionnaires. Adolescents with CFS completed questionnaires again approximately 3 months later.

Results: Adolescents with CFS scored higher on all unhelpful cognitive and behavioural subscales than adolescents with asthma. Parents' cognitions about their child's symptoms were associated with adolescent's own cognitions. Unhelpful cognitive and behavioural responses, particularly damage beliefs, predicted subsequent fatigue in CFS, and all-or-nothing behaviour, catastrophising and damage beliefs predicted subsequent physical functioning.

Conclusions: Unhelpful cognitive and behavioural responses to symptoms appear to be particularly prominent in adolescents with CFS. There is some consistency but not a perfect match between cognitive and behavioural responses to symptoms reported by adolescents and their parents. These responses could be contributing to fatigue maintenance and disability.

Keywords: parents; cognitive behavioural therapy; psychosocial functioning; catastrophising; all-or-nothing; damage beliefs

Background

Chronic Fatigue Syndrome (CFS) is a disabling condition. Adolescents with CFS experience significant and debilitating fatigue, lasting for at least 3 months, which is not explained by another medical condition nor by ongoing exertion. Their fatigue may be accompanied by pain, post-exertional malaise, poor memory and concentration, nausea and dizziness (NICE, 2007). CFS impacts significantly on education; around two thirds of children and adolescents seen for an assessment at a specialist CFS unit were attending less than 40% of their educational provision (Crawley & Sterne, 2009).

Although evidence-based treatment for CFS is relatively effective in adolescents, a considerable minority do not recover despite specialist treatment. A naturalistic study found that children and adolescents with severe CFS took an average of 38 months to recover (Rangel, Garralda, Levin, & Roberts, 2000). After 2 years, half of those affected by CFS remained ill despite routine medical care (van Geelen, Bakker, Kuis, & van de Putte, 2010). Treatment trials for CFS have found that around two thirds of adolescents treated using cognitive behaviour therapy (CBT) were significantly improved after 6 months (Chalder, Deary, Husain, & Walwyn, 2010; Knight, Scheinberg, & Harvey, 2013; Lloyd, Chalder, & Rimes, 2012; Nijhof, Bleijenberg, Uiterwaal, Kimpen, & van de Putte, 2012). Thus, around one in three adolescents remain ill even after treatment; it is important to understand what factors perpetuate the illness and resultant disability.

Cognitive behavioural models of fatigue in adults postulate that cognitive factors, including thoughts and beliefs about the symptoms of the illness, activity and self-efficacy, and behavioural factors, such as inactivity, may contribute to illness maintenance (Browne & Chalder, 2006; Butler, Chalder, Ron, & Wessely, 1991; Chalder, Butler, & Wessely, 1996; Stahl, Rimes, & Chalder, 2014). For instance, if an individual experiences fatigue, and interprets this as being indicative of having a significant disease (damage beliefs), they may avoid activity in an attempt to feel better and to

prevent further harm. This behavioural coping response of inactivity can result in physical deconditioning, exacerbating the effects of subsequent activity. Patients may also focus more on their symptoms (symptom focus), and begin to fear doing activity, believing that it will make their symptoms worse (catastrophising). The behavioural coping strategies, combined with the cognitive responses, can result in their feeling anxious, frustrated, helpless and out of control. This may lead to further unhelpful behavioural strategies, either of prolonged inactivity, or periods of over-activity when an individual feels relatively well, resulting in symptom exacerbation or "payback" (all-or-nothing, also known as "boom-and-bust" patterns). Both behavioural patterns of prolonged inactivity (avoidance/rest) and boom-and-bust (all-or-nothing) exacerbate the symptoms further, creating vicious cycles. CBT for CFS aims to address these vicious cycles by establishing a consistent approach to activity, gradually increasing activity levels, and addressing unhelpful thinking processes (Browne & Chalder, 2006).

Theoretical models of CFS in adolescents, based on the aforementioned adult models, also postulate that cognitive and behavioural factors contribute to illness maintenance (Chalder, Tong, & Deary, 2002). Studies have found evidence of unhelpful beliefs in adults with CFS (Cella, White, Sharpe, & Chalder, 2013; Stahl et al., 2014), but very little research has been conducted investigating cognitive and behavioural responses to symptoms in adolescents, and therefore, the theoretical assumptions of the cognitive behavioural model of CFS in adolescents remain untested.

The scant evidence that does exist in adolescents with CFS/ME indicates the potential importance of cognitive factors in illness maintenance. In a small but well controlled study, children and adolescents with CFS worried more about their illness than juvenile arthritis patients or emotional disorder patients (Garralda & Rangel, 2004). In a large sample of children, adolescents and young adults with self-reported CFS recruited via a self-help website, illness perceptions (e.g. longer expected timeline and worse consequences of the illness) were associated with poor physical

functioning and poor quality of life (Gray & Rutter, 2007). A qualitative study of adolescents with CFS talked about how beliefs about activity contributed to the exacerbation of their CFS symptoms; for example, participants reported that doing too much was unhelpful for managing their illness (Richards, Chaplin, Starkey, & Turk, 2006). Thus, the evidence points towards the importance of illness beliefs in potentially exacerbating symptoms in adolescents with CFS. However, as these existing studies recruited self-selecting samples, and eligibility criteria did not necessarily include the full diagnostic criteria for CFS, the generalisability of the findings is limited.

There is a dearth of evidence pertaining to the behavioural responses of adolescents to CFS symptoms. Whilst paediatric CFS patients reported using problem-solving for common problems, they did not appear to apply these as readily to illness and disability-related problems, to which they responded with more resignation (Garralda & Rangel, 2004). Hareide, Finset, and Wyller (2011) investigated the beliefs and coping strategies of adolescents with CFS using qualitative methods in a small sample; rest was seen as beneficial but was also reported to perpetuate fatigue. Participants recognised that overexertion made their fatigue worse, and therefore, most used a flexible and responsive approach to managing their activity levels. Whilst this demonstrates the potential importance of behavioural responses, the small sample size and the lack of formal measures limits the generalisability of these findings. In a larger sample, adolescents with CFS were significantly more likely to favour rest rather than exercise than those with inflammatory bowel disease (IBD), and this was associated with more severe functional impairment and fatigue (Richards, Turk, & White, 2005). Unfortunately, the full diagnostic criteria for CFS, requiring the presence of fatigue for at least 3 months, were not applied, and there was also a sampling bias towards participants from higher social classes, limiting the generalisability of the findings.

Parental beliefs and their behavioural responses to illness shape those of their children (Turner-Cobb, 2013). Children learn by observing and imitating significant others, particularly their parents,

and parents may reinforce particular behaviours that the child displays (Bandura, 1977). Thus, the child's own cognitive structures or "schemas" develop, at least partly, through the social cognitive process of interacting with others, particularly parents. Adolescence is a key developmental stage during which individuals are normatively expected to begin to develop different ideas and beliefs to those of their parents. They also become increasingly able to take ownership over managing their health (Turner-Cobb, 2013). Little is known about the beliefs of parents of adolescents with CFS and whether they are related to those of the adolescents themselves.

The existing literature provides some glimpses into the beliefs and behavioural responses of parents of adolescents with CFS. One study found that most paediatric CFS patients and their parents attributed CFS primarily to biological causes. Parents dismissed the possibility that psychological issues maintained CFS. These factors were associated with poor outcomes (Garralda & Rangel, 2001). Another study reported that parents of paediatric CFS patients did not think rest in response to fatigue was a useful coping strategy any more than parents of paediatric inflammatory bowel disease (IBD) (Richards et al., 2005), in contrast to adolescents with CFS who tended to favour rest as a coping strategy. In another study, parents of adolescents with CFS were found to reinforce illness behaviour more than parents of children with juvenile rheumatoid arthritis and healthy controls (Brace, Scott Smith, McCauley, & Sherry, 2000). None of these studies directly compared adolescent-parent beliefs at dyadic level, so it is not possible to draw any conclusions about the relationship between parental beliefs and those of their children with CFS.

Thus, cognitive and behavioural responses to fatigue may be relevant to fatigue maintenance, and could be important to target in treatment. It may be that parental responses are related to those of their adolescent children. Understanding more about the cognitive and behavioural responses to the symptoms of CFS in adolescents and their parents could enable the refinement of management and treatment strategies. Therefore, this study aimed to investigate the cognitive and behavioural

responses to symptoms in adolescents with CFS and their parents compared to an illness control group, adolescents with asthma, and to explore the predictive value of these variables over a follow-up period. The research questions were:

1) Which cognitive and behavioural responses to symptoms in adolescents with CFS are associated with fatigue?
2) How do the cognitive and behavioural responses to symptoms in adolescents with CFS compare to those of adolescents with asthma?
3) Are the cognitive and behavioural responses to symptoms reported by adolescents with CFS themselves associated with those reported by their parents?
4) Which cognitive and behavioural responses to symptoms in adolescents with CFS predict subsequent fatigue and functioning at follow-up?

Based on the existing literature, we hypothesised that higher levels of catastrophising, damage beliefs, symptom focus, avoidance/rest and all-or-nothing behaviour would be associated with greater fatigue. We expected to find that adolescents with CFS endorsed more unhelpful cognitive and behavioural responses to symptoms than adolescents with asthma. We also anticipated that the responses of adolescents would be associated with those of their parents. We expected that an adolescent's symptom focus, catastrophising, damage beliefs, avoidance/rest and all-or-nothing behaviour would predict fatigue and functioning.

Method

Participants

All participants were adolescents, between the ages of 11 and 18. Two groups of participants were recruited; a CFS group and a group of asthma patients. Asthma was chosen as a control group as it is a chronic illness, which has a number of parallels with CFS in that it has a fluctuating and relatively unpredictable course and requires ongoing medical monitoring. Symptoms may flare up periodically.

Consecutive attenders at two specialist CFS units were invited to participate between August 2010 and December 2012, with data collection continuing at one unit as part of routine clinical practice until January 2017. A total of 207 adolescents (age 11-18) attended the units, of whom 135 met the eligibility criteria for this study by virtue of having a clinician confirmed diagnosis of CFS based on the NICE guidelines (NICE, 2007). One hundred and twenty one (89.6%) of the eligible participants contributed data for this study. Of these, 110 mothers and 72 fathers also completed questionnaires.

The asthma patients were recruited from GP surgeries between August 2010 and December 2012. The GP practices identified eligible participants who used medication for asthma. These patients were contacted by letter and invited to participate. 28 participants completed the questionnaires, one of whom was subsequently excluded as they were ineligible (did not have asthma), resulting in a sample of 27 asthma participants.

Measures

Basic demographic information were gathered.

Cognitive and Behavioural Responses to Symptoms – The Cognitive and Behavioural Responses Questionnaire or CBRQ (Moss-Morris & Chalder, 2003) is made up of 40 items. Respondents are asked to what extent they agree with a series of statements (e.g. 'I am afraid that I will make my symptoms worse if I exercise') on a 5 point Likert scale (0 = strongly disagree, 4 = strongly agree). It forms 7 subscales (Ryan, Vitoratou, Goldsmith, & Chalder, 2018), 5 of which are cognitive responses (fear avoidance, catastrophising, damage beliefs, embarrassment avoidance and symptom focusing) and 2 of which are behavioural (all-or-nothing behaviour and avoidance/resting). Higher scores indicate more unhelpful cognitive and behavioural responses. This measure has not previously been used with adolescents, but several studies have used this measure in adults including in the context

of CFS (Ali, Matcham, Irving, & Chalder, 2017; Chalder, Goldsmith, White, Sharpe, & Pickles, 2015; Ingman, Ali, Bhui, & Chalder, 2016; Knudsen, Henderson, Harvey, & Chalder, 2011). In adults, the CBRQ has been shown to be valid and reliable when subjected to psychometric evaluation (Ryan et al., 2018). In the current study, Cronbach's alpha for each of the subscales was ≥ 0.70, apart from the damage beliefs subscale in the asthma participants, which was 0.55 (see supplementary materials S1. for details). Parents completed an adapted 5 subscale version of the CBRQ; the subscales completed by parents were 3 cognitive response subscales (fear avoidance, catastrophising, damage beliefs) capturing the parental beliefs about their child's symptoms, and 2 behavioural response subscales (all-or-nothing behaviour and avoidance/resting) on which parents were informants on their child's behaviours (See S1.). The internal consistency of these subscales completed by parents ranged from 0.67 to 0.88 (see S1. for details).

Fatigue – the Chalder Fatigue Questionnaire, CFQ (Chalder et al., 1993) assesses fatigue severity. It contains 11 items each of which are rated on a 4 point scale (0-3). Respondents are asked to think about the past month, and higher scores indicate more severe fatigue. It has good reliability and validity in adult samples (Cella & Chalder, 2010) and has been used previously in studies of adolescents with CFS (Chalder et al., 2010; Crawley et al., 2017), including in treatment trials (Brigden et al., 2016; Lloyd, Chalder, & Rimes, 2012). In previous studies, Cronbach's alphas of > 0.7 have been reported (Lloyd, Chalder, & Rimes, 2012; Lloyd, Chalder, Sallis, & Rimes, 2012) Cronbach's alpha in the current study was 0.89 (CFS participants) and 0.66 (asthma participants).

Physical Functioning –the Short Form 36 physical functioning scale, SF-36-PFS (Ware & Sherbourne, 1992) describes a series of 10 activities of daily living, such as 'climbing one flight of stairs'. Respondents indicate, on a 3 point scale, the extent to which their health limits them in these activities. Lower scores are indicative of greater impairment or disability. The psychometric properties of the SF-36-PFS have been explored in adolescent populations with chronic illness e.g.

cystic fibrosis (Gee, Abbott, Conway, Etherington, & Webb, 2002) and it has been used as an outcome measure in treatment trials in adolescent CFS studies (Brigden et al., 2016; Lloyd, Chalder, & Rimes, 2012). Previous studies have reported Cronbach's alphas of > 0.8 (Lloyd, Chalder, & Rimes, 2012) and the validity of the SF-36-PFS when compared to qualitative reports from adolescents with CFS has been demonstrated (Brigden et al., 2018). Cronbach's alpha in the current study was 0.91 (CFS participants) and 0.72 (asthma participants).

School and social adjustment – the Work and Social Adjustment Scale, WSAS (Mundt, Marks, Shear, & Greist, 2002) captures participation in life. It is composed of 5 items, rated on 9 point (0-8) scales, encompassing functioning in work, domestic, social and leisure activities and close relationships. Higher scores indicate more impairment. 'School/college' was substituted for 'work' in this study, and the examples of the activities given were made more relevant to adolescents. For example, private leisure activities listed as examples were 'reading, watching t.v., listening to music'. This adapted version of the scale will henceforth be referred to as the School and Social Adjustment Scale (SSAS). This adapted version of the scale has previously been used as an outcome measure in treatment trials of adolescents with CFS (Lloyd, Chalder, & Rimes, 2012; Lloyd, Chalder, Sallis, et al., 2012) with Cronbach's alphas of > 0.7 reported.. Cronbach's alpha in the current study was 0.81 for the CFS participants and 0.76 for the asthma participants.

Anxiety – the State Trait Anxiety Inventory, STAI (Spielberger, 1983) is composed of 40 items. Each item is rated on a 4 point scale (1-4). Twenty items assess anxiety felt in response to specific threats or stressors (state anxiety), and twenty items assess general sensitivity to threat (trait anxiety). Higher scores indicate higher anxiety levels. Cronbach's alphas of > 0.85 have been reported for the STAI (Spielberger, 1983), which has been extensively used in adolescent populations (Hishinuma et al., 2001; Smith, Mitchell, McCauley, & Calderon, 1990). The STAI has previously been used in studies

of adolescents with CFS (Smith, Martin-Herz, Womack, & Marsigan, 2003). Cronbach's alpha in the current study was 0.96 in both participant groups.

Depression – the Children's Depression Inventory, CDI (Kovacs, 1992) was specifically designed for use with children and adolescents, and is made up of 27 items. Each item is rated on a 3 point scale with a recall period of the last fortnight (0-2). The items assess depressive symptoms including negative mood, ineffectiveness, anhedonia, low self-esteem and interpersonal problems. Higher scores indicate more depression symptoms. The CDI has previously been used in treatment trials in adolescents with CFS (Nijhof et al., 2012). Cronbach's alpha in the current study was 0.90 (CFS participants) and 0.85 (asthma participants).

Procedure

CFS patients: Questionnaires, and a letter of invitation explaining the use of this data for audit and research purposes were enclosed with the appointment letter and posted to all patients who were offered an initial assessment at a specialist CFS unit. At the assessment appointment, the study was discussed, the patient information sheet shared, and written consent to participate was sought. As this was a naturalistic study within a clinical setting, some participants were not offered a follow-up appointment as they did not require or want it, or were not funded for treatment. Participants who attended follow-up completed the measures again (N = 80, (66% of the original sample). The mean interval between time 1 (initial assessment) and time 2 (follow-up pre-treatment) was 3.3 months (S.D. 2.05, range 0.89 - 13.60).

Asthma patients: GP (family doctor) practices identified eligible participants (i.e. 11-18 year olds who used medication for asthma). These patients were contacted by letter and invited to participate.

Ethical Approval

For the recruitment period August 2010 to December 2012, the research data collected was approved by [information removed for blinding]. Participants gave written informed consent for both the research and audit.

Data Analysis Plan

Data was analysed using SPSS 24.0. Where less than 25% of the data for an individual participant on a specific scale was missing, the mean of the remaining items was substituted for the missing values.

For the cross-sectional group comparisons, the groups were compared on demographic characteristics and variables of interest using independent samples t-tests, with simple bootstrapping (1000 samples) applied to account for unequal variance between the groups. Bivariate correlations (Pearson's, 2 tailed, missing cases excluded pairwise) were conducted to explore the associations between variables of interest. One-tailed tests were used to examine the associations between parent and adolescent scores on the CBRQ as these were expected to be positively correlated. The association between variables was considered to be strong if $r > 0.7$, moderate if $r > 0.5$, and weak if $r > 0.3$ (Rumsey, 2015).

The CFS group was part of a prospective study; a larger sample was therefore recruited. For the longitudinal data, a hierarchical linear regression, informed by the results of the correlations and by theoretical assumptions based on previous studies, was used to look at predictors of change over the follow-up period. Fatigue (CFQ) and physical functioning (SF-36-PFS) were the outcomes of interest. Missing data was excluded on an analysis-by-analysis basis, and fatigue/physical functioning, as well as anxiety and depression, at baseline and time elapsed between the baseline and the follow-up, were included as covariates.

Results

Group comparison at baseline

At baseline, the CFS and asthma groups did not differ significantly in terms of age (see table 1). There was a higher proportion of females in the CFS group compared to the asthma group, which reflects the epidemiology of CFS (Crawley, 2014). Fatigue and impairment in functioning were significantly greater in the CFS group than the asthma group (see table 2).

CFS participants who were followed-up compared to those who were not

At follow-up, 82 (67.8%) of the CFS participants completed measures. Those who were followed up did not differ significantly to those who were not followed up on any measure aside from school and social adjustment (see supplementary materials table S2.). Those who completed follow-up (mean 23.27, S.D. 7.66) were significantly less impaired on school and social functioning than those who did not complete follow-up (mean 26.42, S.D. 8.49, t (113) = -2.00, p = .048).

[insert tables 1 and 2 about here]

Cross-sectional associations at baseline

In CFS participants, fear avoidance, catastrophising and avoidance/rest were associated with physical functioning (SF-36-PFS), and all-or-nothing behaviour was associated with fatigue (CFQ) – see table 3.

[insert table 3 about here]

Group comparisons at baseline

Scores on the 7 subscales of the CBRQ (adolescent self-report) were not normally distributed. A bootstrapped independent samples t-test was used to compare means between participants with

CFS and asthma. Differences between the 2 groups were significant ($p < .001$) on all 7 subscales of the CBRQ (see table 4).

[insert table 4 about here]

Associations between parental report and young person report of cognitive and behavioural responses for CFS participants

With the exception of father-adolescent report of damage beliefs, the CBRQ subscales, between parent and their adolescent offspring, were significantly associated (see table 5). Although the correlations were significant, r was < 0.5 for most subscales.

[insert table 5 about here]

Prediction of change over time in CFS participants who were followed-up

Paired samples t-tests found that fatigue, depression, trait anxiety and school and social functioning did not change significantly over the follow-up period (see supplementary materials S3). Time elapsed from baseline to follow-up was not significantly associated with change in fatigue ($r = 0.12$, $p = .330$). Physical functioning increased significantly (mean at initial assessment 51.64, S.D. 24.69, mean at follow-up 56.03, S.D. 26.43, $t = -2.13$ (77), $p = .036$). Time elapsed from baseline to follow-up was negatively associated with change in physical functioning ($r = -0.27$, $p = .030$). State anxiety decreased significantly (mean at initial assessment 46.95, S.D. 11.92, mean at follow-up 44.33, S.D. 12.99, $t = 2.56$ (81), $p = .012$).

CBRQ subscale scores at baseline which were significantly associated with fatigue at time 2 were fear avoidance ($r = 0.26$, $p = .021$) and catastrophising ($r = 0.22$, $p = .046$). A hierarchical linear regression with fatigue at time 2 as the dependent variable, and time between time 1 and time 2, as well as

baseline (time 1) fatigue, state anxiety, trait anxiety, and depression as a covariates, was conducted. This showed that the time interval between time 1 and time 2, fatigue and mood were the most important factors, accounting for 43% of the variance in fatigue at time 2. The addition of the CBRQ subscales increased the variance explained by a further 7.9%, with damage beliefs particularly adding to the variance explained (see table 6).

When physical functioning at time 2 was considered as the outcome of interest, time interval between measurements, mood and physical functioning at time 1 explained 65.1% of the variance. A further 12% of the variance in physical functioning was explained by the CBRQ subscales. In particular, catastrophising, all-or-nothing behaviour and damage beliefs contributed significantly to improving the model (see table 6).

[insert table 6 about here]

Discussion

This study sought to expand the understanding of cognitive and behavioural responses to CFS in adolescents according to self- and parent-informant report. In the CFS group, higher scores on all-or-nothing behaviour was associated with greater fatigue, and higher levels of fear avoidance and catastrophising were associated with poorer physical functioning cross-sectionally. Adolescents with CFS scored significantly higher on all CBRQ subscales assessing unhelpful beliefs and behaviours than adolescents with asthma. Parental responses about cognitive and behavioural responses to symptoms were moderately consistent with adolescent self-report, with some evidence of individuation. The time elapsed between the assessment points, fatigue, depression and anxiety at baseline, predicted much of the variance in fatigue at time 2. Cognitive and behavioural responses, particularly damage beliefs, added significantly to the variance in fatigue explained. For physical

functioning, damage beliefs, catastrophising and all-or-nothing behaviour significantly contributed to explaining the variance in this outcome beyond baseline functioning, depression and anxiety.

Unhelpful cognitive and behavioural responses to fatigue were more evident in adolescents with CFS as compared to adolescents with asthma. These differences may have been due to higher levels of anxiety and depression in the CFS participants. This is consistent with previous findings from studies which compared adolescents with CFS to those with juvenile arthritis or emotional disorders (Garralda & Rangel, 2004), and those with IBD (Richards et al., 2005). In the current study, it appears that all-or-nothing boom-and-bust behaviour patterns were associated with greater fatigue, and were predictive of poorer physical functioning at follow-up. Previous studies in adolescents with CFS have not specifically assessed all-or-nothing behaviours; instead, adolescents with chronic fatigue have reported a tendency to rest (Hareide et al., 2011). The conflicting findings may reflect a tendency of adolescents to be relatively flexible in the strategies they adopt to manage their health, responding to how they feel in the moment.

In those with CFS, both fear avoidance and catastrophising were associated with physical functioning, which is consistent with previous findings (Richards et al., 2006). Thus, adolescents with CFS who believe that doing more will exacerbate their symptoms, and that their illness is awful, tend to do less. However, it is also possible that being more impaired in terms of how much one can do can lead to more fear avoidance and catastrophising.

Parents' report of their adolescent offspring's cognitive and behavioural responses to symptoms were significantly but moderately associated with those reported by the adolescents themselves. This indicates some degree of individuation, as one would expect during adolescence. It is likely that parental beliefs may have influenced adolescent beliefs. However, the adolescent's temperament as well as other environmental factors will also have influenced their beliefs and coping responses.

Interestingly, the association between father-informant report of the adolescent holding damage beliefs and the adolescent's self-report was weak. This may be explained by the fact that fathers and their children spend less time with each other (Levy, 2011). Also, men on the whole, tend to be more risk-taking and less risk averse than women (Eckel & Grossman, 2008), and therefore may be less likely to hold damage beliefs generally.

Strengths and Limitations

As the CFS group was consecutively recruited from a specialist CFS unit, generalisability to adolescents presenting to specialist services is likely to be good, although generalisability to those managed in primary care and those who are too severe to attend services is unknown. CFS diagnoses were confirmed by a clinician at the initial assessment, rather than relying on self-report or questionnaire measures. Due to the naturalistic design, some participants did not attend follow-up as they did not require treatment or were not funded for follow-up. In total, data was available at follow-up for about two-thirds of the original CFS sample, which potentially could have introduced bias. However, there were few differences between those who were followed up and those who were not. Those who were not followed up tended to report significantly higher levels of fearful beliefs and greater social impairment. Furthermore, there was some missing data as not all participants completed every item of every measure and pro-rating was only performed where less than 25% of the data on a scale was missing. The follow-up period was quite varied between participants although no treatment was offered by the clinics during this time. It is not known what other treatments adolescents might have received through other avenues.

Due to the recruitment method, it is not possible to establish how many patients with asthma were contacted but did not respond; hence, the asthma sample may not be representative of the larger population of adolescents with asthma. Furthermore, wed only included adolescents who used inhalers. The asthma participants were recruited through primary care, rather than specialist

services, and may therefore be less severely affected by their illness than CFS participants recruited through specialist, tertiary services. Future research could utilise a measure of health-related quality of life to enable such comparisons to be made. As the asthma group only completed questionnaires at the first time point, we were unable to make longitudinal comparisons, which constrains the degree to which causality can be inferred from the findings.

Although we selected the best existing measures, psychometric data was not always available for adolescents with CFS and asthma. Different internal consistencies found across the groups in our study might suggest problems with measure comparability in different chronic illness populations in adolescents, or could be due to problems with measurement variance in the measures themselves, making group comparisons inappropriate. The parents completed measures of cognitive and behavioural responses. This was an adapted self-report measure and is yet to be thoroughly examined for reliability and validity.

A strength of the study was the inclusion of both mothers and fathers. However, there was a relative lack of cultural diversity in the sample, and therefore, the results may not be widely generalizable to different cultural contexts.

Implications and Conclusions

Unhelpful cognitive and behavioural responses to symptoms were more prominent in adolescents with CFS than in asthma controls. There was some consistency in terms of views reported by adolescents and their parents. The responses that seemed particularly important were the cognitive tendencies to endorse damage beliefs and catastrophising and the behavioural response of all-or-nothing behaviour. These responses are potentially important in maintaining fatigue and disability in CFS, which adds to the evidence in support of the cognitive behavioural model of fatigue. It may be that believing that the symptoms are indicative of having a significant disease (damage beliefs) and

believing that activity will make symptoms worse (catastrophising) contributes to all-or-nothing, boom-and-bust behaviours, resulting in an autopoietic (i.e. self-perpetuating) loop in which symptoms are increased (Luhmann, Baecker, & Gilgen, 2013). This symptom exacerbation serves to confirm the belief that activity makes symptoms worse and leads to more precaution taking in relation to symptom management. Following a period of rest, the individual attempts to do lots again, creating a vicious cycle.

In CBT for CFS, these vicious cycles are targeted through a programme of stabilising and gradually increasing activity levels (addressing all-or-nothing behaviour), alongside identifying unhelpful thinking and generating more helpful alternatives. Targeting these responses in family-focused CBT (Lloyd, Chalder, & Rimes, 2012), including by addressing ways in which significant others may be inadvertently contributing to the vicious cycles by encouraging the unhelpful responses, may be particularly important for improving outcomes. Similarly, brief family-based CBT for functional abdominal pain decreases both parent and child pain catastropishing, which partially mediates outcomes (Levy et al., 2014). Engaging fathers as well as mothers in the treatment process could be particularly important as fathers were less inclined to hold damage beliefs compared to the adolescents with CFS and their mothers; they could be positive role models.

Table 1. Characteristics of Participants – data shown as N (%) unless otherwise stated

		CFS (N = 121)	**Asthma (N = 27)**
Gender	Male	35 (28.9)	12 (44.4)
	Female	86 (71.1)	15 (55.6)
Ethnic Origin	White British	86 (71.1)	16 (59.3)
	Black British	2 (1.7)	1 (3.7)
	Asian/British Asian	3 (2.5)	2 (7.4)
	British not otherwise stated	11 (9.1)	
	Other European	3 (2.5)	6 (22.2)
	Other	11 (9.1)	1 (3.7)
	Mixed race	4 (3.3%)	
	Not stated	4 (3.3%)	1 (3.7)

Table 2. Baseline scores (young person self-report) and comparison of means between CFS and asthma groups

	CFS mean (S.D.)	Asthma mean (S.D.)	Significance Tests – t (df)	Significance level (p)
Age*	15.01 (1.71)	14.89 (2.24)	0.26 (33.03)	.796
CFQ*	23.20 (5.78)	11.89 (2.71)	15.25 (86.69)	<.000
SSAS Total Score*	24.62 (8.11)	1.93 (3.72)	21.99 (89.40)	<.000
SF-36-PFS*	49.97 (25.09)	88.52 (12.70)	-11.35 (80.84)	<.000
STAI State Anxiety	45.50 (12.59)	34.78 (10.44)	4.12 (145)	<.000
STAI Trait Anxiety	48.04 (11.63)	39.70 (11.39)	3.38 (145)	.001
CDI*	15.72 (8.48)	7.26 (5.76)	6.23 (55.39)	<.000

* unequal variances assumed. 2-tailed tests

CDI – Children's Depression Inventory, CFQ – Chalder Fatigue Questionnaire, SF-36-PFS – Short Form 36 Physical Functioning Scale, STAI – State-Trait Anxiety Inventory, SSAS – School and Social Adjustment Scale

Table 3. CBRQ – fatigue and functioning correlations in CFS participants (n=121) at baseline– Pearson's correlations –r (p)

	Fatigue (CFQ)	**Physical Functioning (SF-36)**
CBRQ fear avoidance	.14 (.124)	-.43** (< .000)
CBRQ embarrassment avoidance	.07 (.431)	-.06 (.527)
CBRQ damage beliefs	.14 (.131)	-.06 (.553)
CBRQ catastrophising	.17 (.068)	-.20* (.034)
CBRQ symptom focus	.08 (.412)	-.09 (.359)
CBRQ avoidance/rest	.12 (.208)	-.19* (.040)
CBRQ all-or-nothing	.23* (.013)	-.15 (.125)

CBRQ = Cognitive and Behavioural Responses Questionnaire
*sig 0.05, **sig 0.01, 2 tailed

Table 4. Comparison of CFS group to asthma group on adolescent rated CBRQ subscales

	CFS mean (S.D.)	Asthma mean (S.D.)	Significance Tests – t (df)	Significance level (p)
CBRQ fear avoidance*	15.21 (3.63)	8.85 (4.90)	6.36 (32.76)	< .000
CBRQ embarrassment avoidance*	9.28 (5.56)	4.15 (4.57)	5.05 (45.29)	< .000
CBRQ damage beliefs	10.38 (3.89)	6.00 (3.10)	6.15 (145)	< .000
CBRQ catastrophising	8.21 (3.43)	2.37 (2.34)	8.40 (144)	< .000
CBRQ symptom focus	12.27 (5.38)	6.56 (5.33)	4.99 (144)	< .000
CBRQ avoidance/rest*	14.60 (5.85)	5.69 (4.36)	8.94 (49.96)	< .000
CBRQ all-or-nothing*	9.18 (4.87)	3.19 (3.40)	7.58 (53.31)	< .000

*unequal variances assumed.

CBRQ = Cognitive and Behavioural Responses Questionnaire

Table 5. Correlations between parent-rated and adolescent-rated CBRQ variables for CFS participants – Pearson's correlations – data shown as r (p)

		Adolescent fear avoidance	**Adolescent damage beliefs**	**Adolescent catastrophising**	**Adolescent all-or-nothing behaviour**	**Adolescent avoidance/rest**
Parent-rated fear avoidance	Mother	r = .345** (<.0005)				
	Father	.376** (.001)				
Parent-rated damage beliefs	Mother		.320** (<.0005)			
	Father		.144 (.116)			
Parent-rated catastrophising	Mother			.302** (.001)		
	Father			.220* (.034)		
Parent-rated all-or-nothing behaviour	Mother				.604** (<.0005)	
	Father				.405** (<.0005)	
Parent-rated avoidance/rest	Mother					.525** (<.0005)
	Father					.481** (<.0005)

CBRQ = Cognitive and Behavioural Responses Questionnaire
*sig 0.05, **sig 0.01, 1-tailed

Table 6. Hierarchical linear model of predictors of fatigue at time 2

	Unstandardised B	**S.E. B**	**Standardised Beta**	**T**	***P***
Outcome: Time 2 Fatigue					
Step 1					
Constant	10.67	3.84		2.78	.007
T1 fatigue	0.50	0.13	0.44	3.95	<.000
T1 CDI	0.35	0.12	0.47	2.91	.005
T1 STAI-state	-0.02	0.11	-0.04	-0.21	.835
T1 STAI-trait	-0.06	0.13	-0.10	-0.42	.674
Time between T1 & T2	-0.54	0.34	-0.17	-1.60	.116
$r^2 = 0.430$, $p < .000$					
Step 2					
Constant	12.47	4.62		2.70	.009
T1 fatigue	0.53	0.13	0.47	4.15	<.000
T1 CDI	0.36	0.13	0.48	2.86	.006
T1 STAI-state	-0.03	0.11	-0.04	-0.22	.827
T1 STAI-trait	-0.07	0.15	-0.11	-0.43	.673
Time between T1 & T2	-0.71	0.35	-0.22	-2.02	.049
T1 CBRQ fear avoidance	0.17	0.22	0.10	0.79	.431
T1 CBRQ catastrophising	0.07	0.31	0.04	0.23	.820
T1 CBRQ Embarrassment Avoidance	0.28	0.16	0.23	1.68	.100
T1 CBRQ All-or-nothing behaviour	-0.18	0.19	-0.12	-0.94	.354
T1 CBRQ Damage beliefs	-0.63	0.31	-0.31	-2.04	.047
T1 CBRQ Symptom Focusing	0.16	0.19	0.13	0.84	.407
T1 CBRQ avoidance/rest	-0.08	0.16	-0.06	-0.51	.615
$r^2 = 0.509$, r^2 change = 0.080, $p = .343$					
Outcome: Time 2 Physical Functioning (SF-36-PFS)					
Step 1					
Constant	13.22	11.82		1.12	.268
T1 SF-36-PFS	0.83	0.09	0.78	9.64	<.000
T1 CDI	-0.25	0.36	-0.09	-0.70	.487
T1 STAI-state	0.32	0.33	0.14	0.98	.332
T1 STAI-trait	-0.42	0.39	-0.18	-1.07	.290
Time between T1 &T2	2.36	1.00	0.20	2.37	.021
$r^2 = 0.651$, $p < .000$					
Step 2					
Constant	18.33	13.40		1.37	.178

T1 SF-36-PFS	0.75	0.08	0.71	9.12	<.000
T1 CDI	-0.17	0.33	-0.06	-0.53	.597
T1 STAI-state	0.37	0.29	0.17	1.29	.204
T1 STAI-trait	-0.50	0.39	-0.22	-1.28	.207
T1 CBRQ fear avoidance	-0.47	0.59	-0.07	-0.79	.434
T1 CBRQ catastrophising	-2.35	0.81	-0.32	-2.92	.005
T1 CBRQ Embarrassment Avoidance	0.04	0.43	0.01	0.09	.933
T1 CBRQ All-or-nothing behaviour	0.99	0.50	0.18	1.97	.055
T1 CBRQ Damage beliefs	2.21	0.82	0.29	2.72	.009
T1 CBRQ Symptom Focusing	-0.03	0.50	-0.01	-0.05	.957
T1 CBRQ avoidance/rest	-0.40	0.41	-0.08	-0.96	.340
$r^2 = 0.771$, r^2 change = 0.120, p = .003					

CBRQ = Cognitive and Behavioural Responses Questionnaire, CDI – Children's Depression Inventory, CFQ – Chalder Fatigue Questionnaire, SF-36-PFS – Short Form 36 Physical Functioning Scale, STAI – State-Trait Anxiety Inventory, SSAS – School and Social Adjustment Scale

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